

GUEST EDITORIAL

Opening the door to older consumers: Pandora's box or the way ahead?

In 1945 Vannevar Bush made a report to the President of the U.S.A. in which he argued for the value of basic and public welfare research in the post-war era (Bush, 1945). Since then, the research industry has burgeoned, albeit with constant appeals for greater funding. Alongside this growth in research, the consumer movement has also grown. Since the 1970s, for example, the “consumer/survivor” movement in the U.S.A. has been calling for greater roles for people with mental health disorders in the running of their mental health services. This movement was one result of a societal change towards empowerment of people in what some considered to be an authoritarian, hierarchical system of health care provision. In the late twentieth and early twenty-first century, the two movements have started to collide, as consumer groups request more transparency and a bigger role in research funding allocation, and researchers ponder the merits of consumer involvement in their highly technical fields of expertise.

What is the future role for consumers in research? Do they have a role in all types of research, especially in so-called “blue sky” and “basic” research? The issues are essentially those of transparency of public funding allocation, and who should hold the power to drive research in the right directions to achieve the best outcomes.

Consumers can be involved in research at a number of different levels. Gill (2007) noted that consumer involvement in research ranges from low-level roles, such as receiving brochures, newsletters and other information, to partnership, where consumers are involved in all stages of the research, to more executive roles such as assigning priorities for research areas. In some fields, the importance and value of involving consumers in research is well recognized, while in others, especially in the biological and basic sciences, consumers have yet to play any significant role apart from a passive one. In dementia research, Alzheimer's Australia recently announced the Quality Research in Dementia Care Network, in which consumers will have a close role with researchers. A similar role is undertaken by consumers in the Alzheimer's U.K. group, where consumers are strongly involved in deciding which

research topics and which grant applications to fund. In the dementia area, it appears that only a narrow range of consumers are interested in having a strong role (Doyle, 2008).

In public health research, consumer consultation can be of benefit to researchers as well as the general public. Consumers who understand the target group can ensure the intervention is acceptable and feasible and therefore more likely to succeed. A recent Cochrane Review found that involving consumers in the development of patient education made the material more readable, relevant and understandable to patients (Nilsen *et al.*, 2006). Consumers can also direct researchers to investigate those treatments and therapies that are more likely to be taken up by the target population. For example, by consulting with a group of 112 people with osteoarthritis of the knee, a group in Bristol in the U.K. found that most of them sought treatment via physiotherapy (63%), education (53%) and complementary therapies (23%). However, their literature review revealed that only 15% of research into osteoarthritis of the knee focused on these approaches (Tallon *et al.*, 2000). The implication was that research should follow more closely the inclinations of consumers to provide evidence for or against the preferred treatments. Is this an appropriate use of public research funds? It may be a case of fiddling while Rome burns, as consumers may be very keen on research into treatments based on common wisdom, while less understandable or basic research, which is not funded, might have achieved a cure for the disease more quickly.

Consumer involvement can certainly facilitate recruitment of research participants (Staley, 2009). Consumer consultation is now a requirement of government funding bodies, such as the National Health and Medical Research Council in Australia, and the National Institute for Health Research in the U.K. In these countries, those seeking research funds have to incorporate a consumer involvement component into their studies in order to qualify for funding.

We have recently undertaken two activities at Australia's National Ageing Research Institute (NARI) to identify what older people themselves see as the key issues in mental health. The first was a consumer survey undertaken as part of a

scoping study into older age depression and anxiety for *beyondblue*, the Australian national depression initiative (Haralambous *et al.*, 2009) and the second was a consultation with over 100 older volunteers who attended our annual “Thank-You Day”.

In our older age depression scoping study, a small sample of older men who had experienced depression was asked about their experiences of treatment and their views on future research directions. They reported that their general medical practitioner (GP) was the first port of call for all of them, underlining the important role that GPs play in detecting and managing older age mental health. They had mixed experiences with treatment, some finding medication to be helpful and others preferring to modify lifestyle factors, such as exercise, alcohol consumption or diet. However, their views on future research directions were homogeneous. They sought a focus on prevention and alternatives to medication, including exercise and social programs. They also pointed to the need for greater public awareness of depression. “More publicity should be given to well-known people who have dealt with or are dealing with depression . . . The stories of every day Australians should be told too. The public should be reminded that depression is an illness and . . . sufferers can still play an important role in society.”

In our volunteer consultation, research staff facilitated informal discussions (over afternoon tea) about aging research generally, with the aim of identifying what the volunteers saw as important directions for future research. In the table discussions, older age mental health emerged as an important issue, with most groups wanting to know more about normal memory decline and about how to retain optimum memory function into older age, “*researchers should investigate and tell people what the first signs of Alzheimer’s disease are so that they can say goodbye to their family and prepare themselves*”. Interestingly, gender differences, men’s health, relationships and sexuality were extensively discussed. Questions about gender differences in aging were asked at a number of tables, including “*Is the onset of Alzheimer’s disease the same for men and women?*” “*What factors contribute to older women living longer than older men?*” and “*Is meaningful occupation equally important for men and women?*” Questions were asked about older age mental health consequences of being single compared with being married or being in long-term relationships and the need was identified for more research into sexuality in older age, particularly in same-sex relationships. Older widowers wanted to know more about how to stay socially engaged once they had lost the social connectivity afforded via their wives. Volunteers saw research into environmental factors that can promote or impede older people’s ability to engage

in the community as important. Finally, they asked for research into the benefits of everyday activities such as laughter and gardening as antidotes to depression and anxiety.

Like the older men in the depression study, the main focus of the NARI volunteers was on health promotion, and the need to understand more about how lifestyle factors, such as, physical activity, diet, cognitive stimulation and social engagement can assist in preventing mental health problems in older age. Apart from a question about medication side effects and symptoms, no one sought further research into the bio-medical aspects of aging.

Neither of these groups could be considered representative of the older Australian population as a whole, but the similarity of the messages gives food for thought. Clearly most people, when asked, will have an opinion about what is important to research. The question for future researchers is: how best can we acknowledge public opinion about research priorities? A recent analysis of the Australian National Health and Medical Research Council’s funding allocations conducted by the Australian Association of Medical Research Institutes showed that less than 1.5% of total research funding was allocated to preventive medicine and less than 10% on public health research in 2008 . This compares with approximately 25% on clinical medicine and science and 40% on basic science (Research Australia, 2009). Is this the right mix, and does it reflect public opinions on priorities for research? If our two recent studies above are anything to go by, far more research funding should be allocated to health promotion and primary prevention research.

A more fundamental question is: should public research funding priorities match public opinions about priorities, or is there a better, if less democratic, way to drive research directions? If research funding bodies are serious about consumer consultation, there may be a need to further consult with consumers and to fund a research program in the areas identified by them, namely preventive and public health research above. But we also need more research about how best to involve older consumers, the evidence of the impact of involving older consumers in research, and public discussion on how the priorities for research funding should be decided. Otherwise important “blue-sky” and “basic” research, which is out of reach of the public mind and not easily described, is likely to languish behind more popular topics.

The expectation to involve consumers in research is growing, but consumers should only be one source of information in setting the research agenda as they may not be fully aware of all the research already conducted in the field or of the potential of unfamiliar approaches. It may be that the increasing role of consumers changes the way that research is

carried out, and is another significant step in the evolution that brought researchers from lonely ivory towers into large multi-disciplinary multi-site teams of experts.

Conflict of interest

None.

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